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**Making use of historical case material – the problems of looking back and the implications for service development in relation to research and evaluation activities**

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## **Abstract**

This methodological paper details the process of embarking on a follow-up study of young people with sexual behaviour problems who were known to services in the 1990s and who are now young adults in their twenties or early thirties. In the context of the importance of such follow-up work, the overall aim and objectives of the funded research project are specified and the challenges presented in setting up research partnerships with service sites, including the negotiation of access and ethical approval, are the subject of overview and reflection. The practicalities of beginning the fieldwork which comprised an initial analysis of historical case material held in the research sites are then detailed and the solutions to the problems encountered are explained. The article concludes by identifying the kinds of questions services and researchers need to consider when wanting to engender or enhance a research culture which is facilitative of this kind of outcome research. These relate to the resources necessary to support a research culture, the requirements of data protection and ethical approval processes, obtaining service user consent to participate in future research, secure but accessible storage of records, staff development and researchers' obligations to minimise disruption to already hard pressed services.

**Key words:** Follow up research; children and young people with sexual behaviour problems; methodological issues; service implications

## Introduction

In all aspects of health and human services work there has been increasing emphasis in recent years on evidence based practice, on the importance of treatment or interventions programmes drawing on evidence from research and evaluation about ‘what works’, about what seems to make a positive difference in the lives of patients and service users (Gould and Kendall, 2007; Hodge *et al.*; 2011; Marsh and Fisher, 2005). Independent bodies, such as the Social Care Institute for Excellence (SCIE) and the National Institute for Health and Clinical Excellence (NICE), and government linked research funding bodies such as the Economic and Social Research Council (ESRC) and the National Institute for Health Research (NIHR) promote research in furtherance of such aims or disseminate the findings from studies for the benefit of front-line professionals, managers and those charged with driving service delivery. In professions such as medicine, and in other well established fields of health and social welfare provision, policy and practice are, to a greater or lesser degree, more firmly based on findings from research and evaluation activities but, inevitably, in newer fields of human services provision, many questions about practice and outcomes still remain to be addressed.

Work with children and young people with sexual behaviour problems in the UK is one such relatively recent field of endeavour (Masson and Hackett, 2003) although, since the early 1990s, there has been a steady, if geographically patchy, growth of services in the statutory, voluntary and private sectors to address the consequences of such behaviours. Considerable work has been undertaken to improve delivery of assessment and intervention programmes, but there has been limited UK empirical research of a follow-up nature. This is in contrast to the US where there have been various attempts to establish recidivism rates and outcomes in

groups of treated and non-treated adolescent sexual offenders over the short and/or medium term (see, for example, Bonner *et al.*, 1999; Letourneau *et al.*, 2008). However, there has been little in-depth research, either in the UK or internationally, which has tried to establish the longer term developmental trajectories of children and young people with sexual behaviour problems after the involvement of child welfare or youth justice agencies has ceased and when the young people concerned have moved into young adulthood (Beckett, 2006; Masson and Hackett, 2003; Vizard, 2007).

Such follow-up research is important. If research focuses primarily on the seemingly small minority of young sexual abusers who re-offend (Letourneau *et al.*, 2008) and, in the absence of any data on the majority of young sexual abusers who enter into adulthood without persistent sexual behaviour problems (Chaffin, 2008), policy may become skewed towards an unwarranted focus on risk. As a consequence, intervention responses on offer to individual young people may be unnecessarily intrusive and may fail to distinguish between those young abusers with extensive needs, as opposed to those who may need only a limited professional response. Research is also needed which explores processes and mechanisms that contribute to positive outcomes for young people who were previously the object of professional concern. Our current study, on which this article is based, is attempting to make a contribution to this gap in our knowledge.

### *Overall aims of the study*

The overall aim of our ESRC funded study is to describe and analyse the experiences and life circumstances of young adults who, in their childhoods, were subject to professional interventions because of their problematic sexual behaviours, and to consider the implications of these experiences for future policy and service delivery. The research is ongoing and the process has involved and is involving:

- a. Analysis of available retrospective case file material relating to all children and young people referred to participating specialist intervention projects between Jan 1<sup>st</sup> 1992 and December 31<sup>st</sup> 2000;
- b. Identification, tracing and recruitment of approximately 12 ‘information rich’ cases meeting the criteria for inclusion in subsequent interviews from each of the participating sites, to a target sample of 100 subjects;
- c. Semi-structured interviews, where possible, with professionals who worked with each of the sample former service users and/or their parents and carers;
- d. In-depth interviews with the recruited ex-service user participants (including, where appropriate, parents and carers), comprising a mix of narrative interview and semi-structured interviewing; completion of a range of standardized psychometric measures with participants to identify key features of their current social circumstances and personal functioning; and where ex-service user permission is given, analysis of official statistics and criminal offence data.

Follow up studies after a number of years have elapsed and longitudinal designs (where subjects are followed up at regular intervals) are important for knowledge development and

evaluating outcomes but they are notoriously difficult to do for reasons of, for example, sample attrition (Elliott *et al.*, 2008; Robson, 2001; Ruspini, 2002). Such studies are even more difficult when the intention to follow-up is not 'built into' work with service users and their families at the time of involvement with them. This may well be the case in agency contexts where a 'research culture' may not be developed or be seen as important to develop (perhaps due, understandably, to more pressing priorities such as offering and delivering a service in the immediate). As the research team, we knew that in the later stages of the research, there would be very sensitive ethical issues involved in trying to make contact with ex service users in ways that would guarantee their privacy and current life circumstances but we had not fully anticipated the practical and ethical problems of 'just' looking at archived case material.

Thus, this article focuses on the process of completing the first stage of the project, studying historical case material. The preliminary work involved in embarking on any research project involving collaborative relationships with external organisations and human subjects is outlined, before describing the specific challenges we encountered in accessing and gathering data from the records themselves. As a result of our experiences, we summarise the aspects which human service providers and those involved in research should attend to when planning to look back on a project's earlier work and follow up on outcomes over time, as well as making some suggestions to services about what to consider when planning to build the cultural and practical infrastructure needed within broader programme development to allow for the possibility of such research in the future.

## **Getting started – building partnerships with services**

Alongside an increased focus on evidence-based practice, there has also been much more emphasis placed on the importance of researchers (from within academia and elsewhere) forging partnerships with providers of services and, indeed, with service users in order to make whatever research or evaluation is done relevant to ‘the real world’, that is, relevant to the interests and imperatives of those in need and those trying to meet that need through professional responses (Lowes and Hulatt, 2005; Robson, 2001; Shaw, 2005). In the original research proposal we expressed our intention to ensure that a range of service providers were approached to reflect the diversity of provision in this field. We anticipated that each of the sites would have operated since approximately 1992 and throughout the 1990s. The co-investigators had completed a major study of service provision in the UK and the Republic of Ireland in relation to this population (Hackett, *et al.*, 2005) and so had a good overview of the agencies available nationally and were well placed to recruit participating sites from their existing database of providers.

A total of eight organisations, between them providing more than thirty specialist projects, were contacted and asked to consider participation in the main study. Two of the organisations were nationally based large children’s charities offering a range of services to children and families but including a number of long-standing specialist projects, each of which would constitute an ‘agency site’ for the purposes of our study. One target site was a specialist team within a statutory social services department and another was based within an NHS Trust. The remaining four organisations contacted comprised dedicated specialist



services, based in the private sector. These various target sites were dispersed geographically across England and Wales, and, between them, offered community-based and/or residential provision. They were typically at least part funded by local authority monies and often had contracts with one or more local authorities to provide a service to them primarily, as well as accepting 'spot purchasing' arrangements with other local authorities on a case-by-case basis. The private sector organisations were more likely to accept referrals from across the whole of England or even the UK.

Information about the study was provided verbally by the research team over the telephone, and a follow-up email and further information were then sent to the relevant manager in each agency site. Our contacts were asked to provide written e-mail confirmation if they were able to give 'in principle' agreement to take part in the main study. Where multiple projects within a national organisation were approached, contact was made both with the local service manager and the senior manager with national responsibility for such specialist services (in one organisation) as well as the senior managers for research and development in both organisations.

Both national organisations gave their 'agreement in principle' to participate in the project. Within each of these organisations, there were at least 4 potential specialist sites in which we could base the main research study because they met our inclusion criteria and our local contacts with these sites indicated that there was a great deal of enthusiasm for the research to go ahead. Similarly, following negotiations, the six smaller and equally suitable specialist sites, both private and statutorily based, gave their 'agreement in principle' to becoming

involved in the project. It was understood that more detailed negotiations about access and ethical approval to proceed were still required, but, for the purpose of securing funding to proceed with the project, 'agreement in principle' statements were sufficient.

In summary, we were delighted with the level of support for the study. It appeared to generate an enormous amount of interest in the field, with services often responding to our initial written information with great enthusiasm, a number commenting on the lines of 'we've never had time to really get into this kind of work but had wanted to do so'. Such positive responses to attempts to improve the evidence base for this area of work were also apparent in the survey-based research conducted by two of the previous authors (Hackett *et al.*, 2005) and bodes well for the future of the field.

### **The next steps – negotiating ethical approval and complying with Data Protection legislation**

With any research project involving human subjects, there are important processes of ethical approval which must be successfully negotiated before fieldwork can begin. Those conducting research and those (service or other) partners collaborating with the research must be able to demonstrate that in the research proposed there will be appropriate systems in place to, for example, guarantee the safe and confidential storage of data of whatever form and to obtain the informed consent of those from whom data is sought (the subjects of the research). The anonymity of subjects must be ensured (unless there are overriding issues of safety to them or others which require reporting, a possibility which subjects must be made

aware of before giving informed consent), as well as that of services, in subsequent reports and publications. Mechanisms and procedures must be put in place to ensure that no harm befalls subjects or researchers in the process of doing the research and also that psychological supports are in place if they are required. Such ethical considerations, or as Robson (2001) calls them ‘rules of conduct’ (p 65) are essential to the integrity of the whole research effort. Various professional groupings have developed ethical codes of conduct which provide useful guidance to all involved in research with human participants (see, for example, British Psychological Society, 2009 and British Sociological Association, 2002).

In addition to the above considerations, the requirements of the Data Protection Act 1998 must be complied with where data is being collected that identifies a living individual although, as soon as personal identifiers are removed from the research data, the legislation no longer applies. The Market Research Society and the Social Research Association (SRA) have produced a helpful guide to the requirements of the Act (SRA, 2005) and the Information Commissioner’s Office (ICO) website (at <http://www.ico.gov.uk/> ) provides copious information on what are very detailed and not always well understood regulations. The Act’s eight key principles are closely aligned with the ethical issues discussed above and require organisations that process personal data to abide by the Act’s requirements, and to notify the ICO about the purposes, including that of research, to which personal data is being put, and with what safeguards.

The process of negotiating and securing ethical approval and meeting data protection requirements is often complex and, indeed, these issues may resurface during the lifetime of a

research project as unforeseen ethical dilemmas or challenges arise. In addition, where approval has to be sought from a number of organisations, somewhat repetitive and time consuming processes are involved, for which allowance of anywhere between three to six months, we would estimate, must be made in an overall research project timetable. Such organisations typically include the relevant funding body (in our case, the ESRC), universities if the researchers are from that work base, and any potential partner organisations.

In our study, we initially had to provide the ESRC with reassurances that we were fully cognisant of the ethical issues relevant to our research aim and objectives and, following ESRC approval to proceed, we had then to secure more detailed ethical approvals from our respective universities via their research governance processes, as well as negotiating the research governance processes of the services who had agreed in principle to participate in the project. These processes were variable. With one national organisation an 'expedited' process was used because university ethical approval had already been given. All the university paperwork had to be submitted to the organisation which then considered it via its own rigorous research governance procedures before giving the go-ahead to proceed. The other national organisation adopted what might be described as a 'lighter touch' and gave the go-ahead on the basis that university ethical approval had been granted and on the basis that individual service managers were in agreement that their respective team be involved in the research. The four privately run services had their own local ethical approval panels or Boards of Trustees who gave their approval to proceed on the basis of the information the research team submitted (including evidence of university ethical approval) and discussion of any issues the services raised.

Negotiations became much more protracted, problematic and ultimately unsuccessful, in the case of the service based in an NHS Trust and in relation to the team which was part of a local authority children's service. In the case of the former, it is anecdotally well understood by social researchers that NHS research governance processes are notoriously detailed and time consuming, appearing sometimes to be overly bureaucratic and, occasionally, even irrational or unreasonable (Hammersley, 2009). As regards our experience, following many months of slow progress in just the 'foothills' of the Trust's research governance system, the research team had to decide not to pursue that target site due to time pressures; the effort being expended was not matched by any optimism that we would ultimately be successful in obtaining approval.

In the case of the local authority (LA) children's service, there was much correspondence and a meeting in the local authority over a period of 4 months to discuss the worries and concerns the LA had about obtaining consent of subjects, matters of confidentiality and anonymity and the like, although it was clear that individual staff (in the target team and in research governance) were sympathetic to our proposal. However, in the end, the LA's decision making body eventually decided that it was not willing for the research to go ahead. The formal reason given was that the human resources deemed necessary to meet information governance requirements did not exist in the LA, although the nature of these requirements was not specified. Informally, it was commented that the timing of our request was unfortunate in that LA was particularly sensitive about any activity which might potentially result in adverse publicity, post the high profile and tragic case of 'baby Peter Connelly' in another local authority and the subsequent media and governmental fallout (Parton, 2010).

So, as a result of all these negotiations, the research team found itself with the necessary ethical permissions to proceed with the research in relation to the two national organisations and the four privately run services. These in themselves provided a very useful mix of provision but it was a matter of regret that our sample had narrowed somewhat and would not include any health or direct local authority provision. We shall never know whether the cases these services dealt with were similar and/or different to those in our sample and in what ways, but such setbacks are a common feature of doing research – decisions and strategy have to be made on the basis of what is do-able.

### **Getting down to fieldwork –practicalities, problems, solutions and outcomes**

Following further discussions within the two national organisations, four long-standing specialist teams within one of the national organisations were selected for inclusion in the project and one specialist team from the other national organisation, based on our inclusion criteria. These were scattered across England. Of the four privately run services, three were in various parts of England and one was in Wales.

Of these nine project sites, three out of the four privately run services had well established research cultures and had either already conducted their own research on various aspects of their work or had commissioned or collaborated with external researchers to get such research completed. In relation to the national organisations, both had research governance

dedicated staff and processes at a national level but this culture had not taken particular or long term seed within local specialist services. Without exception, service managers and staff we met were enthusiastic towards what we wanted to do but it appeared that their understanding of the importance of research and evaluation work had not translated itself into immediate service priorities, nor had it necessarily contributed to systems facilitative of such research. These differences did impact on the ease with which we were able to execute the first stage of the research, the retrospective initial analysis of historical case file material.

### ***Secondary analysis of pre-existing data***

Documents are one variety of secondary sources which researchers may draw on in their work, secondary sources being defined by Forcese and Richer as ‘pre-existing or pre-recorded data which were not collected for the specific ends of a given social researcher’ (1973: 179). As such, documents are an example of non-reactive or unobtrusive measures, ‘undisturbed by the presence of the researcher’ (Shipman, 1981: 126). There is increasing interest in the use of secondary analysis based on such pre-existing documents, official statistics and other artefacts (Corti, 2007; Hammersley, 2010; Long-Suthehall *et al.*, 2010; Prior, 2008)) and, with the development of systems for the electronic archiving of official and other public documents, there is much more potential for the safe and ethically appropriate saving of a range of such material which has historical interest and which can be revisited by future researchers (Corti, 2007; Gibbs and Hall, 2007). Patient medical records and social work records in their raw form would and should never be considered for such public archiving but, with the ethical and data protection safeguards already discussed, they can provide valuable data for the researcher in specific projects.

It is suggested (Prior, 2008; Robson, 2001) that there are various ways in which documents (and indeed secondary sources generally) may be used: as ends in themselves, providing all the data for a complete study; as partial data for a study; or as validation or a check against a researcher's own data. In our study we wanted to use historical case records as partial and beginning data, our aim being to complement analysis of this material with interviews, ten or more years later, with adult ex-service users, carers and others. We planned to use the case files as references for information about the ex service user and their family circumstances at the point of referral to a service, about the kind of programme they were offered and about how those involved in the work with the service user had assessed the young person's future prospects at the point of closure. There has been debate amongst historians and sociologists about the extent to which written case records can be used to critique social work practice (see, for example, Floersch, 2000) but in our study it was not our intention to critique the work of the services – our interest was in gathering relatively basic data about the population known to a given agency or service back in the 1990s as a baseline or starting point for then conducting our follow up study of a smaller sample of now adult ex-service users to try and understand how they were faring in later life and what factors might be contributing positively or negatively to their life trajectories.

### ***Practical resources available***

In order to collect the data from the historical case files, which was needed to undertake the subsequent analysis, members of the research team travelled to the research sites to either



gather the necessary data from hard copies of the files or from electronic files. All the sites were very welcoming and they were most helpful in terms of providing some temporary work space, access to refreshments and electric sockets to which we could attach our laptops. In one case the files were stored in a secure storage facility without access to electric power, natural light or a working surface and so this was slightly more problematic. A fully charged laptop battery was needed and data gathering had to be conducted in four-hour bursts, to allow for battery (and researcher) recharging.

In terms of other practical resources, it proved to be invaluable when a site had kept a referral book or simple database of some kind which provided basic details, such as name of service user, date of referral, which worker had handled the referral and reference to any associated case file identifier. This made the locating of the archived case material relevant to our time period much easier. What we were also delighted to discover was that in at least six of the nine sites, a significant number of practitioners, managers and/or administrators had been in post during our research time frame. Such staffing stability probably indicates something about the quality of service provision and the nature of staff commitment; for us as researchers, such continuity of staffing was extremely useful in understanding the organisation and ethos of the service back in the 1990s and in checking out queries about particular case files.

### ***Retention of records***

There were noticeable differences in how well records had been retained, ordered and stored. In the national organisation where four sites were involved in the research, the records in two

of the sites were problematic; in one case, no paper files had been retained at all and, as many of the 1990s cases had not been migrated into electronic storage, there was only access to a few electronic files. There was also no comprehensive list of the cases worked with in the period in which we were interested. In the other site, there was a list of all the 500 cases which the service had dealt with over the years but no reason for referral was noted and so it was very hard to distinguish the cases of interest to the research team, as opposed to the other kinds of work the service undertook with children and families. Again, many of the early cases had not been migrated into the more recent electronic records system. In contrast, and to our delight, the cases files for the other two services in this national organisation had all been retained, carefully ordered and securely stored and were readily made available to us at the site offices. This happy state of affairs, from a research point of view, applied also in the four privately run services.

In the second national organisation, the research site had only retained about a third of the paper case files for reasons which were not clear, although a well ordered referral book was in existence. Some strategy meeting information about the missing cases was held in the host local authority but, following 4 months of negotiating with the LA lawyers, access was still unforthcoming and so the decision was made to abandon the quest and just focus on the third of cases that were available for audit.

### *Completing the data collection forms*

At this early stage in the project we aimed to collect information from the files about the young person's gender, age at referral, any disability, legal status at the point of referral (for

example, whether the young person was in custody or local authority or family care), the nature of concerns about the young person's behaviour, a range of basic information about their victims and, finally, whether the case file contents were such that it could be described as an 'information rich' case and suitable for further analysis.

Actually completing the data collection forms, where there were case files in paper or electronic format, was relatively straightforward although time consuming. Particularly in the case of early electronic files, data in which we were interested were sometimes missing and, in general, it appeared that in the 1990s some data had not been regularly collected, such as ethnic minority status, or had been very variably or imprecisely collected, such as information about any learning disability.

One important issue, which was raised by one of the research sites, related to data protection issues and whether the research team should have access to names and addresses without consent being sought first from the human subjects concerned. According to data protection legislation, it became clear that such consent should have been sought, even though all personal identifiers to the initial data we collected and have been analysing were immediately separated from the rest of the data and all subsequent results are of a summary nature, with no individuals or research sites identifiable. Nevertheless, as a result of clarification of data protection regulations, in the next stage of the research, contacting of ex service users and family members to invite them to participate in the research is being undertaken by staff in the research sites themselves, rather than directly by research team members.

## ***Outcomes***

Notwithstanding the challenges described above, the research team was able to gather data on some 700 cases across the nine sites, probably the largest database of this kind in the UK.

Analysis is ongoing and the results will be published in due course but successful completion of this first stage was essential in order to progress to the next phases of the study: the identification of a smaller sample of information rich cases, leading to the tracing and recruitment of ex-service users, now young adults in their twenties or early thirties, with a view to completing in-depth interviews with them and possibly members of their families, complemented with interviews with the professionals who knew them back in the 1990s.

## **Discussion and implications for services interested in research and evaluation activities of these kinds**

As overviewed in the preceding discussion, there are many aspects to a research project such as ours to which attention must be paid: building partnerships with potential research sites; negotiating often ongoing and complex processes of ethical approval and data protection; working out the practical arrangements for fieldwork and problem-solving obstacles as they arise (Abbott and Sapsford, 1998; Robson, 2001). An overriding concern in all research which involves human subjects is that no harm must be done to those involved and so allowing sufficient time to work out difficult issues and dilemmas as they arise is essential.

As indicated, without exception, all the service sites we have been working with have been enthusiastic about the research endeavour and ready to cooperate, although we have been anxious to keep any time commitment on the part of service staff to a minimum, being conscious of the daily work pressures practitioners and managers face. It was clear, nevertheless, that there was a more established research culture in some sites than in others, as a result of which progress in some sites was less problematic than in the rest. In this context, we suggest that services unused to conducting or being involved in research, might want to consider the following questions as part of any strategy to develop such research and evaluation activities:

- How important do we see our contribution to research and evaluation activities in the field (in relation to our mission and priorities)? If we do see them as important:
- What additional resources have we got or can we identify to promote a research culture?
- Have we notified under Data Protection legislation for our data (collected for clinical/service delivery purposes) to be used in research? If no, should we be notifying the Information Commissioner's Office, and what is the process for so registering our research intentions?
- Do we routinely provide the necessary information in order for service users to give formal informed consent to:
  - a) their (anonymised) data being used for research and evaluation purposes?
  - b) to their being contacted in later years for the purposes of follow-up research?

If no to a) and/or b), what information should we provide and what should a consent form look like?

- What (if any) is our process for considering (internal or external) proposals for research and evaluation activities? What ethical approval processes should we employ? What guidance can we access and, if part of a larger organisation, what advice and policy may already be available?
- (In relation to closed cases) what is our policy about the archiving and secure storage of such information in a manner which will facilitate future research and evaluation work? What personalised data and other data are we going to retain and in what form? What Data Protection considerations must be taken into account? Whose job in the service/organisation should it be to keep archived data secure, sufficiently detailed and accessible for future, approved research projects?
- What practical resources may we be able to offer internal and external researchers?

Thus, in order to further the development of evidence-based practice, we are suggesting that those charged with the development and delivery of services to those in need should make space for research and evaluation as part of their missions and business plans. In addition there is a need for enhanced training for professionals in order for them to be able to critically assess research and to undertake research as part of their regular activities (Abbott and Sapsford, 1998; Sharland, 2009; Shaw, 2005).

Equally, researchers must be sensitive to the pressures under which services work and the fact that research and evaluation are not a primary part of their mission or business. Thus it behoves external researchers to take full responsibility for progressing the research ethically

and conscientiously, with as little disruption to services as possible and without adding to their regular workloads. In this context, from a research point of view, at least having a much more standardised process for obtaining ethical approval across human service providers and shared agreements about assessment criteria would be more efficient and less time-consuming but such a state of affairs is unlikely to be achieved in the short or medium term. In the meantime, there are commentators who have questioned the wide remit and role of ethics committees and their capacity to make sound judgements about individual research proposals and who have argued that ever-increasing regulation may have the negative consequence of preventing potentially worthwhile and well thought out research (Hammersley, 2009; Tierney and Corwin, 2007).

## **Conclusion**

This article has sought to illuminate the process of doing follow-up social research within a number of specialist assessment and intervention services working with children and young people with problematic sexual behaviours. Whilst some of the matters discussed are specific to this particularly sensitive service user group, many of the issues highlighted also arise in social research with other service populations, where the research may have other aims and objectives. It is hoped that this account of the preliminary work needed to launch a research project is illuminating for those involved in human service delivery who may have had no previous direct experience of research involvement. In addition, the article offers a checklist of issues which services might usefully consider which would facilitate the undertaking of such research in the future. Such research is important in terms of adding to our knowledge base about longer term outcomes for service users and about the implications for future service development.

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